



Information for families

Making an informed choice

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Informed consent vs informed choice

- **Informed consent** is a legal construct concerned with the information provided to the patient (“a reasonable person standard”) rather than the values or preferences of the patient.
- “An **informed choice** is one that is based on relevant knowledge, consistent with the decision-maker’s values and behaviourally implemented” (Marteau et al., 2001)

Informed choice

- “Informed choice” is not synonymous with information that is neutral or functionally descriptive. Rather, **evaluative information** is essential in that it draws attention to the various risks, benefits, and uncertainties related to particular options.

Moeller, M. P., Carr, G., Seaver, L., Stredler Brown, A., & Holzinger, D. (2013). Best practices in family centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, 18, 429-445.
<https://doi.org/10.1093/deafed/ent034>

Information provision \neq Understanding

Providing information

Abhyankar, P., Volk, R. J., Blumenthal-Barby, J., Bravo, P., Buchholz, A., Ozanne, E., Vidal, D., Col, N. F., & Stalmeier, P. (2013). Balancing the presentation of information and options in patient decision aids: an updated review. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S6. <https://doi.org/10.1186/1472-6947-13-S2-S6>

Best available evidence

- Information should be based on **best available evidence**
- **Best available evidence** = based on a high-quality synthesis of the available evidence that is relevant to the patient's clinical situation and acknowledges where uncertainty exists because of the quality or quantity of that evidence.

Balanced manner

- Information should be based on best available evidence...presented in a **balanced** manner – in content, in format, and in display
- **Balance** = complete, unbiased and neutral presentation of the relevant options and the information about those options – in content, in format, and in display
- **Unbiased** = presentation in a way that places equal weight on positive and negative information and avoids placing judgment on the information.

Other considerations - Consequences

- Communication
- A lifelong commitment requiring lifelong services and supports
- Ongoing financial implications
- Education

- Birdsey, B., & Joseph, L. (2021). Plurality of perspective: DOCTOR-PARENTS of deaf children in a low-to middle-income COUNTRY. *International Journal of Pediatric Otorhinolaryngology*, 110610. <https://doi.org/https://doi.org/10.1016/j.ijporl.2021.110610>
- Porter, A., Creed, P., Hood, M., & Ching, T. Y. C. (2018). Parental decision-making and deaf children: a systematic literature review. *Journal of Deaf Studies and Deaf Education*, 23, 295-306. <https://doi.org/10.1093/deafed/eny019>
- Porter, A., Sheeran, N., Hood, M., & Creed, P. (2021). Decision-Making Following Identification of an Infant's Unilateral Hearing Loss: Parent and Professional Perspectives. *International Journal of Pediatric Otorhinolaryngology*. [https://authors.elsevier.com/sd/article/S0165-5876\(21\)00215-9](https://authors.elsevier.com/sd/article/S0165-5876(21)00215-9)

WHAT ARE OUR LIMITATIONS?

- LATE IDENTIFICATION
- LATE / NO INTERVENTION
- UNEQUAL EDUCATION OPPORTUNITIES



Credit: Families and children of Thrive
- <https://www.thrivesa.org.za/>